Seizure Tracker - a Data Resource to Improve Clinical Trial Design

Interagency Collaborative to Accelerate Research on Epilepsy (ICARE)

April 26, 2018

Robert Moss
Co-Founder of SeizureTracker.com
Father to Evan who lives with TSC

Free Online

24,000+ Global Users
250+ New Monthly

2,300,000+ Events Logged
1000+ Events Daily

45,000+ Medication Entries

Profile information
Age, gender, diagnosis (patient reported), etc.

Therapies
Medication, Rescue Medication, Diet, VNS, etc.

Logging Apps

Android Mobile
Apple Mobile/Watch (NCH Collaboration)
Alexa Home/Wearables/Etc.

Mobile Interface

Features…
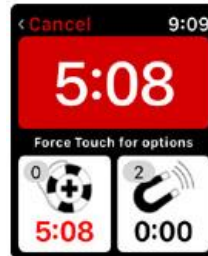Real Time Seizure Event Logging
Video Capture
Graphs
Log Offline
Sync At Your Convenience

Easy Access = Better Data

Apple Watch

Accessibility
Nationwide Children's Collaboration
Simple Recording Interface/App Hand Off

Amazon Alexa
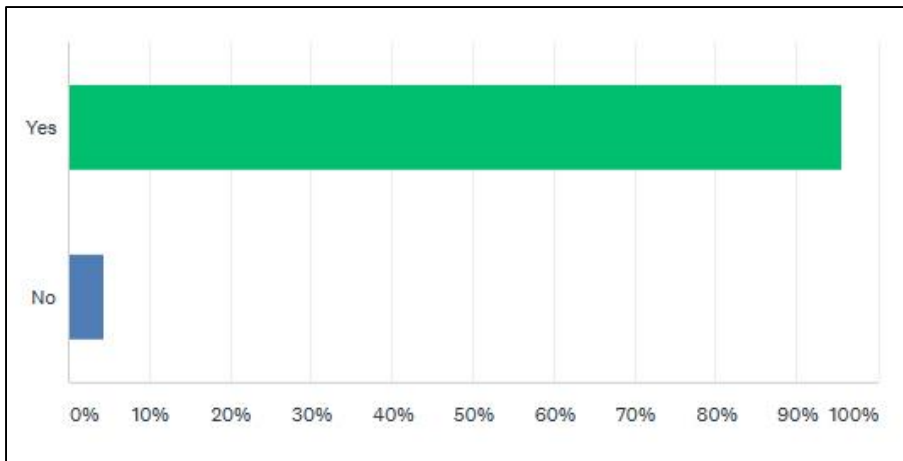
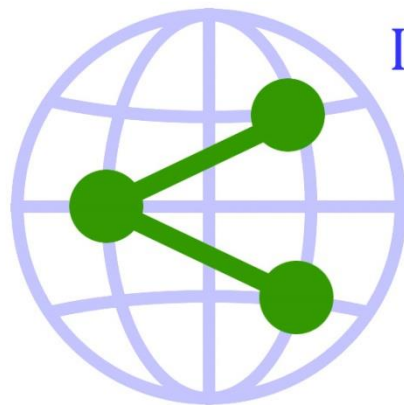Tell Alexa to track your seizures

Big Data?

11 Years of Historical Data
2,300,000+ Events Logged
1100+ Events Daily

Research Mandate

Would you be willing to share your anonymous Seizure Tracker data with researchers if you thought it would help develop new treatments for Seizures and Epilepsy?

International Seizure Diary Consortium

Current Projects

Beth Israel Deaconess:
Natural variation
Seizure duration
Placebo Effect
Natural History

Boston Children's
Diurnal variation
Seizure duration
Seizure prediction

Mayo Clinic
Multiscale seizure patterns

Albert Einstein
Cluster properties
Determinants of seizures

Mt. Sinai / NYU
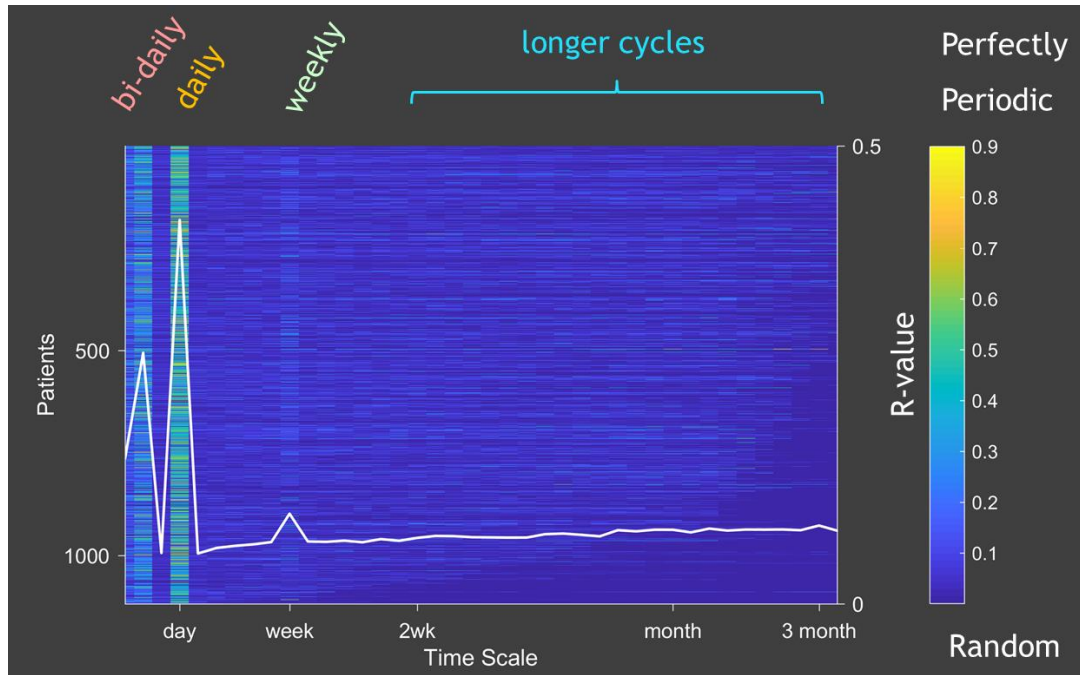Clinical trial models

Washington University
Rational polypharmacy

Melbourne University
Low frequency patterns

www.seizuretracker.com/SeizureSuccess

Multi-day cycles

Circadian and circaseptan rhythms in human epilepsy: a retrospective cohort study
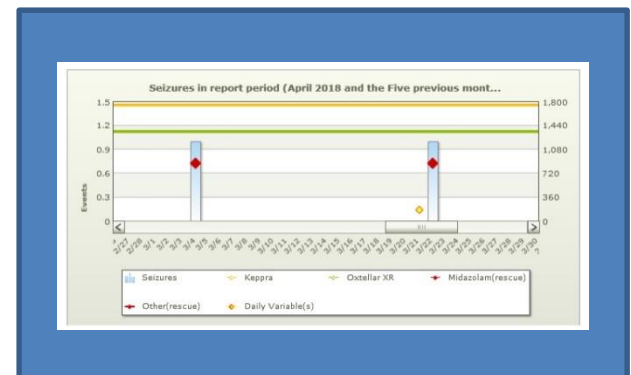Philippa J Karoly LANCET NEUROLOGY NOVEMBER 01, 2018

Self-reported seizures

>1000 patients
10 years of recording

Cycles are highly prevalent
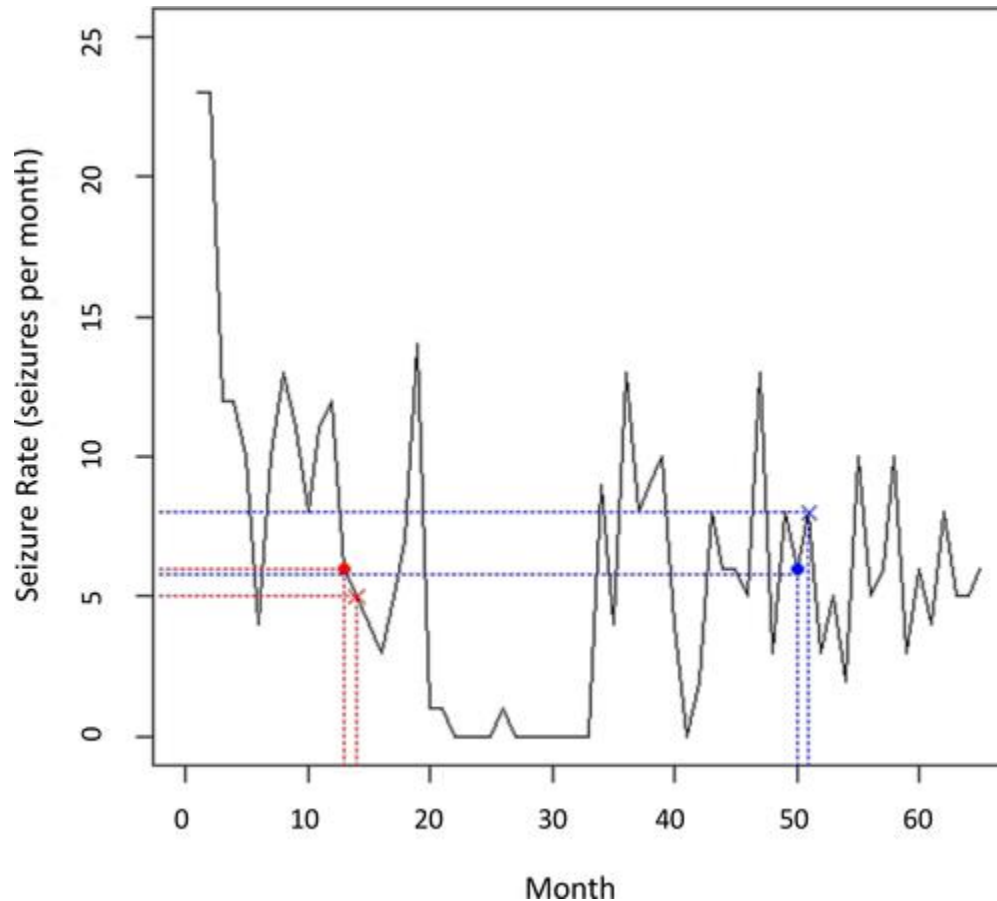86% circadian
26% 7-day cycle

Seizure Risk States
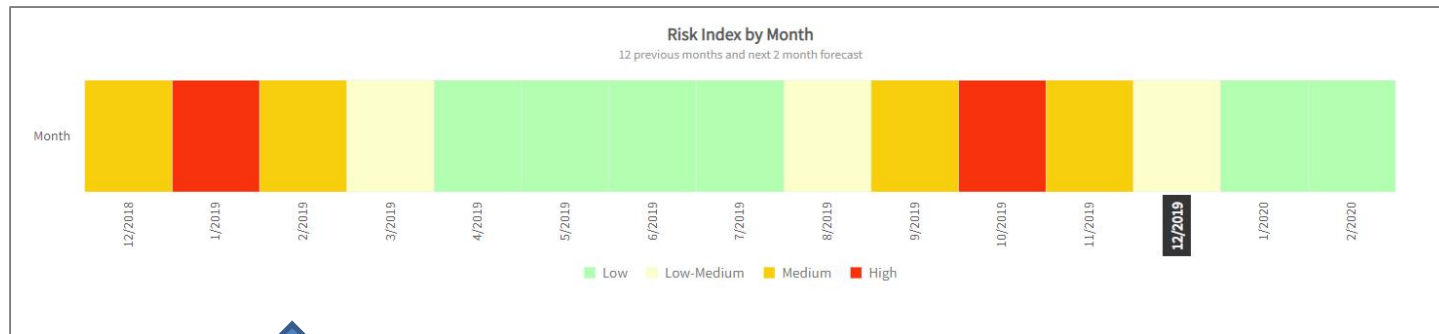
TSC population
Identified four risk states
Transitions/Trajectory

Seizure Risk States

Risk Index by Month
12 previous months and next 2 month forecast

Month

1/2018 | 1/2019 | 2/2019 | 3/2019 | 4/2019 | 5/2019 | 6/2019 | 7/2019 | 8/2019 | 9/2019 | 10/2019 | 11/2019 | 12/2019 | 1/2020 | 2/2020

Low   Low-Medium   Medium   High

Leverage for timing of enrollment
Understand impact of seizure risk on placebo/therapy

Seizure Risk States

Risk Index by Month
12 previous months and next 2 month forecast

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1/2018 | 1/2019 | 2/2019 | 3/2019 | 4/2019 | 5/2019 | 6/2019 | 7/2019 | 8/2019 | 9/2019 | 10/2019 | 11/2019 | **12/2019** | 1/2020 | 2/2020

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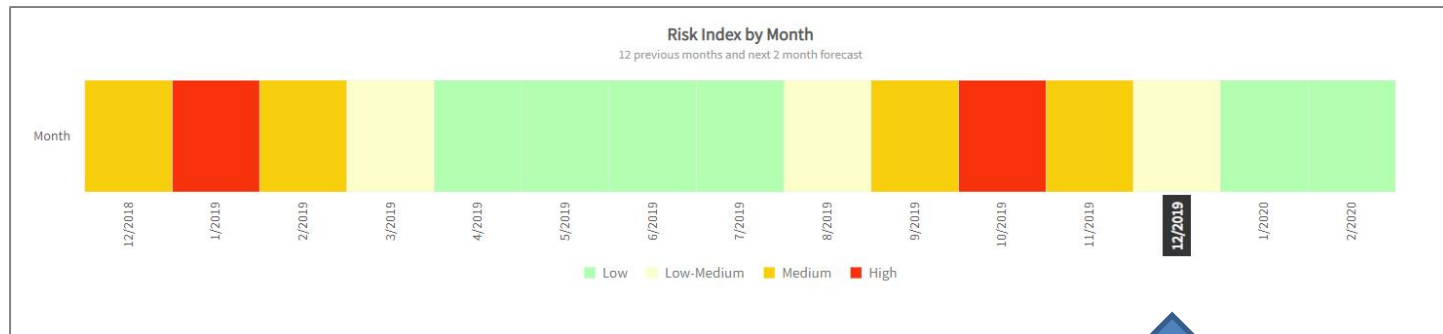
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Zv method
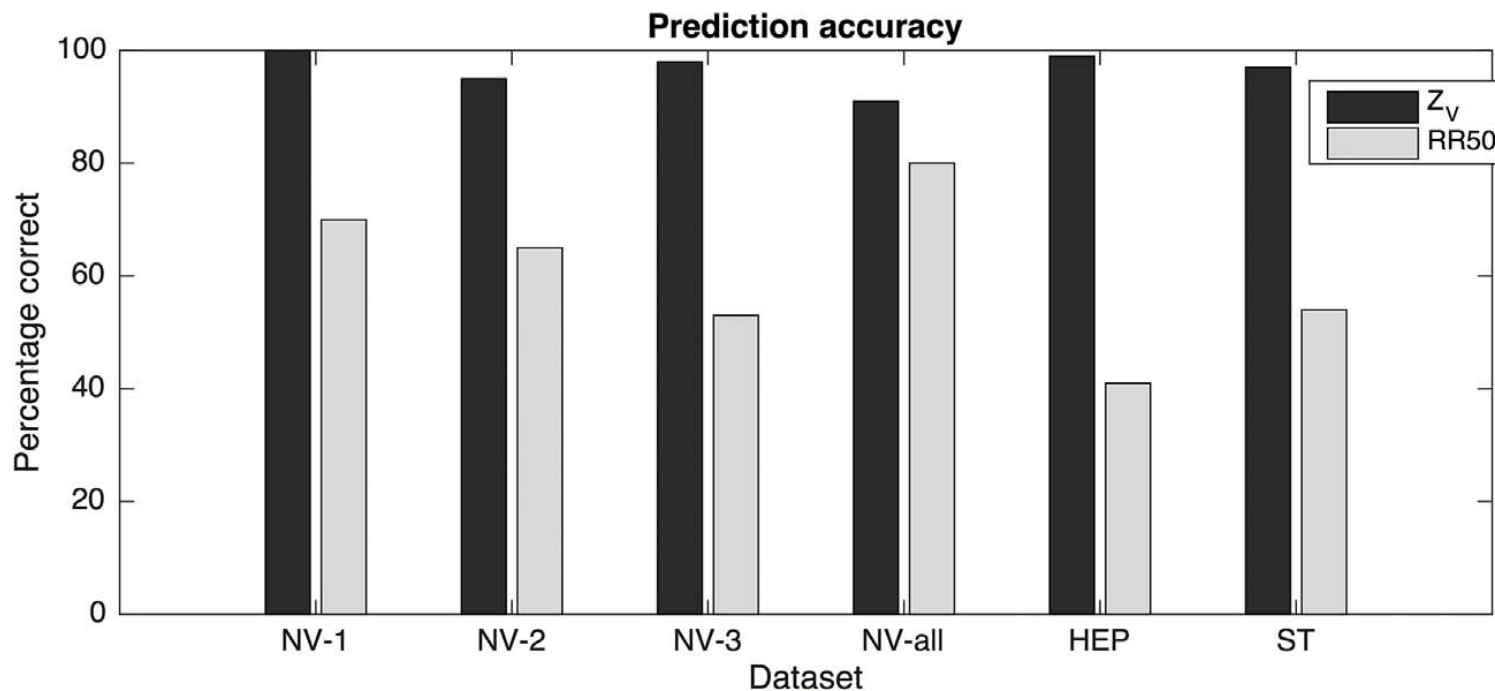
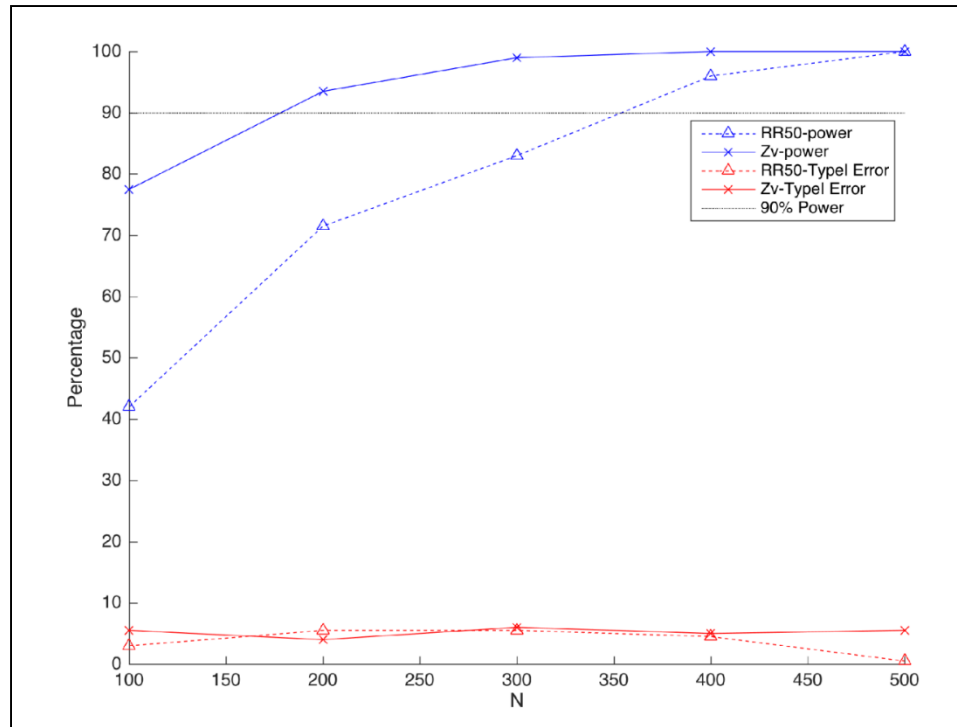Prediction accuracy across datasets was, Z_V: 91–100%, RR50: 42–80%. Simulated RCT Z_V analysis achieved >90% power at N = 100 per arm while RR50 required N = 200 per arm.

Zv method
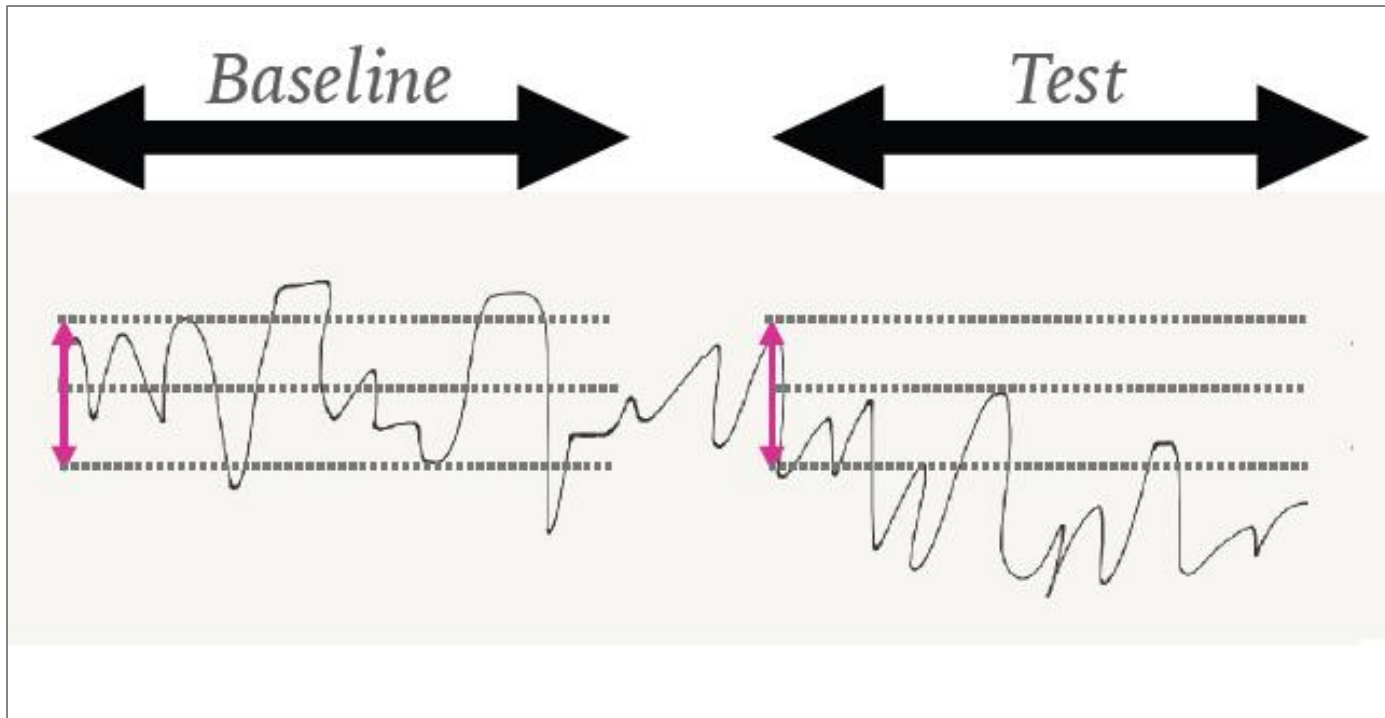
Measure baseline variability
Establish confidence intervals
Predict test variability
Generate normalized Z scores

Zv method

Participant count for 90% accuracy

Potential benefits of electronic diary usage

Individualized profiling/results
More accurate data
Reduce trial size
Possibly eliminate baseline evaluation period
Targeted recruitment

ST Data Share Program/Study management

Thank You!

Contact:

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